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How Standards will Degrade the Concepts of the Art of Medicine.

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Abstract. The paper is dealing with the problematic positioning of the whole health care system towards the concept of standard. There is a constant quest for standards, and a prediction of how everyday language gradually will disappear. It is the assumption and conjecture of this paper that as we outdo everyday language from our communication in the system we loose major part of meaning-construction concerning health and life of the patient/citizen. It is the normative and ethical aim of the discussion to frame how human factors are terminated as standards and bodies as machines replaces everyday language and bodies as carrier of health. Hans Georg Gadamer has led me on the way through inspiring essays on the Enigma of Health.

Keywords. Standardization, Phenomenology of time and space. Health.

Introduction

At an EHR conference held a couple of years ago a plenary was discussing the qualities of standards as a tool in health care informatics, and the director of a Danish Non-governmental Organization “Kræftens bekæmpelse”, which is an organisation that represents patients with cancer, and their relatives, Arne Rolighed said out loud: “We do not consider ourselves standards!!” (Annual Conference of the EHR Observatory 2006. October 27th) So if we as designers and developers of EHR/PCIS put a focus on standard, then we loose both knowledge layered in the single physician and nursing staff and we reject the idea of implementing the patient citizen in this vital process. The mathematical and geometrical outline of the current editions of EHR means that the individual is locked in an objectivist and accumulating vision on time and space.

Phenomenological time and space is quite different and as the Austrian novelist Robert Musil writes in *The Man without Qualities* (1954): “The train of events is a train unrolling its rails ahead of itself. The river of time is a river sweeping its banks along with it. The traveller moves about on a solid floor between solid walls; but the floor and the walls are being moved along too, imperceptibly, and yet in a very lively fashion, by movements that his fellow-travellers make” [1].

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1. Communication and interaction in the hospital system

Apparently there is an unbridgeable gap between the two ontologies – the Euclidian mathematical and geometrical and the phenomenological –, but the Russian physicist and Nobel prize winner Iliya Prigogine, writing about the concept of time, sees an opening within the scientific world towards phenomenology: “It is remarkable to recognize the extent to which some of the recent results (of natural science) had been anticipated by philosophers like Bergson, Whitehead and Heidegger. The main difference consists of the fact that they could reach such conclusions only in contrast to natural science, whereas we are now observing that these insights emerge so to speak from scientific research” [2]. Prigogine recognizes an outreach from the sciences toward phenomenological everyday life practices, and as such the bridging in between the technical and scientific realm of medicine and the social and personal life of patients and staff in the hospital system, has been undertaken. The evidence of this bridging is still fairly weak and has to be supported and enhanced in order for the banks to be united. The bridge is a construct made out of language, physical interaction, time and space, which makes it complicated and to a high degree dependent on the actual context. We are ‘moved by our fellow-travellers’, as Musil wrote [1].

Doctors communicate with nurses and secretaries in a formal and glaciated language, based on medical Latin. As they revolve their attention to the administration, of which they are themselves an integrated part, they switch to a technical language of economics and management that does not fluctuate or get translated in the system. Doctors’ communicating to patients is of course at hand at ward-rounds and in outpatient departments, but more often the decisions and plans made by the doctor are translated into everyday language by either the nursery staff or the secretary.

The major issue of this specific discussion is to deal the inappropriate outdoing of everyday language, and we find that theories concerning the appropriateness of implying everyday language as a parameter in constructing computer systems is at hand.

One of the major criterions for development of successful CSCW (Computer Supported Cooperative Work) is the criterion of double level language: “applications should support at least two interacting levels of language”: a “cultural” (“informal”) and a “formal” level, which are complementary (which means that they both support and outdo each other!!). The “formal” level provides clarity, predictability, and a “common reference point”; the “cultural” level provides room for interaction and interpretation, “doubt and imagination” [3]. The health-professional is becoming a traditional scientist that communicates and documents, as experts should in what Gibbons et al. named ‘mode 1’ disciplinary science, and at the same time produces facts in a ‘mode 2’ fashion coining the rationality of medicine with that of economics and management. [4]. Where do we put the imaginative and creative act of *wondering* if we take away the language of wonders, metaphors and a like? What becomes of the art of medicine if every action and statement has to be conformed to a regulatory of standards?

The French philosopher Michel Serres states quite rightly in a conversation with Bruno Latour that: “Technical vocabulary seems even immoral: it prevents the majority from participating in the conversation, it eliminates rather than it welcomes, and, further, *it lies* in order to express in a more complex way things that are often simple. It

does not necessary lie in its content but in its form, or, more precisely, in the rules of the game it imposes" [5]. Serres takes it a step further in *The Parasite* (1980): "When history and time are measured by the calculation of exchanges and brought back to this calculation, I fear that here and there will be some insolvents. People who can give nothing than their children, their muscles, their bodies, a pound of flesh. It is a time of death and of history of death" [6]. The practices of medical science coined with the rationality of calculation in a 'mode 2' stance are transferred and layered in the technological system of the hospital, which has a decisive saying in the objectification of our sick and disturbed bodies.

Technology has become independent *res extensa* replacing the body in a Cartesian sense, where the mind and intellect governs interaction and communication. When we create systems in order to regulate and control practices and procedures in health-care we have to be aware of the ontology of systems, because as Serres states: "The system is non-knowledge. The other side of non-knowledge. One side of non-knowledge is chaos; the other, system. Knowledge forms a bridge between the two banks. Knowledge as such is a space of transformation" [6]. We create systems in order to cope with what we do not yet understand. This means that we constantly have to work with the system in order to escape ignorance and furthermore avoid the rigidity of standards, manuals and protocols, because they will inevitably freeze and black-box the system, preventing the transformational force of bridging knowledge, i.e. the art of medicine.

We are on the path of denial of body and experience on behalf of technical rationality and analytical dismantling of the body machine, as personal illness is diagnosed into the abstract realm of universal disease [7].

The fairly abstract, yet forceful and provocative, thoughts and ideas of Michel Serres could be complemented by a line of thought by the German philosopher and father of modern hermeneutics Hans Georg Gadamer who in 1989 gave a lecture on "Treatment and Dialogue". Time has gone by since the late eighties, but the core statement of the lecture has not become less relevant: "In order to preserve this important recognition of distance, doctor and patient must gain some common ground where they can come to a mutual understanding. Such common ground can only be provided by the dialogue they sustain between themselves" [8].

In the modern world, however, the opportunities for doctor and patient to enter into genuine dialogue with one another are extremely limited [8]. Seen in the light of this rightful statement it becomes highly problematic, that the overall focus on standards as epistemological back-ground for EHR's seems to confirm a prediction made by Gadamer almost two decades ago:

"It can be foreseen that the need of prose language will gradually be diminished as documentation is done in a more structured way" [8].

The anonymity of the power represented in language (standards), as the subject is erased from the discussion, makes the prediction nominal and seemingly objective, hence as something that cannot be changed or discussed. It is a causal systemic effect, beyond our individual will and control. It presents itself as something given and natural, hence reflecting what the German sociologist and philosopher of the modern Jürgen Habermas calls the expansive and colonising "nature" of modern science [9].

Language does not exist without a dialogue, and if dialogue disappears between doctors, support-staff and patients (or even auto-dialogue, where the doctor discusses with himself “Writing whilst thinking”) [10] then no meaning can any longer be constructed concerning the singular patient. According to Gadamer this means that a treatment or ‘careful handling’ as well becomes impossible [8].

The earlier mentioned and cited director of “Kræftens Bekæmpelse”, Arne Rolighed, stated in an interview with the Danish researcher Helle Wentzer (27th October 2006) that: “The most unemployed knowledge in the Danish Health Care system is that of the patient and relatives. EHR should open for possibility. There are immense potentials for improvement of care” [11]. The systemic evolution of EHR is moving in the opposite direction, because the knowledge of patients and relatives cannot be inscribed in the structure as language and standards are externalising health as a concept of personal life.

Gadamer claims on the account of diagnosis and plans made on pure data that the doctor may obtain some knowledge on what to do, but it will only provide guidelines: “Now a modern doctor might well reply that modern medicine is in fact quite able to do this. (Give answer to why a person is not feeling well) One needs only to examine and to record all the various functional life-processes which take place in the body, and perhaps even in the psychological life, of the patient and then compare these results and data with established standard values. But an experienced doctor knows that such a method can only provide guidelines and only supply a preliminary overview of medical findings. A certain caution is always required, along with a more considered examination which also takes into account the patient’s condition as a whole” [8]. The externalisation and alienation of both the doctor and the patient in the rationale of modern medicine is confirmed by the findings and assertions of the Danish researcher Signe Vikkelsø as she writes: “However what become auditable are only those aspects of healthcare, which are rendered *visible and measurable* through the EPR. How patients are actually handled by the healthcare collective and how patients experience this handling will not be elicited in the new information structure” [12].

That the reflection made by Gadamer still counts today is confirmed by Rolighed in the interview, as he states that: “As you meet the doctor and nurse they look at you as a diagnosis and fails to see the whole person and the surrounding network” [11].

On this behalf that act of producing a diagnosis and proceeding in care-taking on the premises of a diagnosis has been criticised: “The medical diagnosis has no room for the patient’s immediate wishes, experience and needs, all of which play a role in determining which treatment is realistic for the patient” [13]. Further down the line it becomes clear how nothing has changed since the lecture given by Gadamer, because: “There seems to be a tendency towards a more objective concept of disease, which to say that more and more diseases are diagnosed on the basis of measurements (e.g. laboratory tests), independent of whether any subjective symptoms exists or not” [13].

The act of gathering data in huge central/national databanks could very well lead to such an increasing pathologization of the population, which again manifests itself in a constant and increasing screening and monitoring of individuals and/or groups. This development can be seen in vast screening of women in search for breast-cancer and on a smaller scale in telemedicine.

2. Conclusions and perspectives

I am not saying that systems and infrastructures should be abhorred because of the casual, but if we ignore the power and potential of casual we will never gain insight and understanding of the world and the connected concepts of realities.

The meaning of introducing the EHR as a tool for both system-development and health-professional procedure is to gain control, certainty and security in an iterative process of rationalisation, but as Chris Shilling [14] and Simon J. Williams [15] has shown: “the more control we have over our bodies, the less certain they become.” It is a paradox which cannot be handled by modern institutionalised medicine and health care and the technologies in the system, because “medicine is still in fact, first and foremost, a modernist enterprise, steeped in a scientific tradition in which truth, order and progress are seen as paramount virtues. Seen in this light, current developments in medical technology represent a further extension of modernist imperatives centred on rational control and domination of “nature” [15].

For what concerns modern institutionalised medicine a communication with the “techies” in IT departments should be possible as they are playing the same language game. It has shown that in the development of various systems super-users from the medical realm has been employed in the actual development which could lead to the assumption that the overall approach to system-design was and is reflecting the “Scandinavian approach” which by involving the user aimed at a democratic, emancipating and empowering design in everyday work-life practice. It is the conjecture and prejudice that the alliance of computer-skilled medical staff and system-developers are creating a game and a language (terminology) that excludes [16] major part of the actual users (unskilled health-professionals concerning both computers and medical terminology) and looks at health as a societal and physical issue and outdoing the health as a condition of the individual on both a physical and metaphysical level. The major reason to this conjecture should be seen in the light of the outdoing of everyday language in the actual record on behalf of standardised and structured terminology, which to a great extent upheaves and make visible the infrastructure of the system. This means that it is the black-box of the system that provides all the data and facts, and obstructs meaningful knowledge-making and bridge-building in between medical staff and lay-people.

At the same time by emphasising the Durkeheimian societal body on behalf of the private body there is an attempt to overcome the *enigmatic* aspect of health [8], which to a great extent is decisive for how we perceive and conceive the very core of health. A core, which is paradoxically and enigmatically invisible and intangible as health is in balance: “We must address the fact that the real mystery lies in the hidden character of health. Health does not actually present itself to us” [8]. Gadamer is as well of the opinion that that the overall aim of standardisation which to a high degree is governing the current efforts within system-development and the political/organisational discussions and decisions is reflecting the major error of modern science: “We are even so bold as to establish so-called standard values, clearly one of the principal sources of error in established medicine” [8].

It is common knowledge, or at least it is a common saying – even among professionals – that “you” get sick going to the hospital and by that we often mean, that there are paradoxically so many bacteria and viruses that our bodies cannot withhold

the reigning condition. But what if it is the processes within the organisation and clinical practice that makes us sick, this is at least what Gadamer claims to be a possible answer. He writes: “The attempt to establish precise correspondence with standard values through medical intervention can actually bring about a deterioration in the patient’s health” [8].

We are travelling on the same train and we are ‘moved by our fellow-travellers’ as the context changes through our movement. Systems, standards, manuals and protocols assure that the train leaves and arrives on time, but tell very little about what we experience through our travelling. The art of medicine should according to the key statements made by Musil, Serres and Gadamer deal with this travelling and a meaningful and caring space for bridging the banks should be integrated part of the construction of open-ended and dynamic digital spaces, where gatekeepers like rigid standards should be kept at a minimum. The final and critical questions remain: How do we get our fellow-travellers in play as we construct EHRs? How do we break the alliance in between medical science and calculation, i.e. standards, because seemingly leading to ignorance and blind mechanization? How do we create meaningful interactional space for communication and understanding in between medical staff and patients/citizens, i.e. how do we bridge the banks through technology?

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